



SPINAL CORD
COMMISSION

SPINAL COURIER

Vol. 9, No. 3

April 1998

Conference '98

Don't wait any longer! If you haven't registered for *Living With Spinal Cord Disability: Strategies for a New Century*, do it now. If you don't, you'll miss the best speakers on spinal cord injury to be in Arkansas for the rest of the century!

The conference is scheduled for **May 1 and 2** at the DoubleTree Hotel in Little Rock. **Mark Wellman**, extreme wheelchair athlete from Truckee, CA, will open the conference with his session entitled "No Barriers." Conference sessions will highlight strategies related to wellness, seating, dealing with secondary conditions, technology and an update from the Social Security Administration. In addition, there will be an exhibition area with the newest products and technology and a resource room.

Ten Continuing Education Units (CEU's) will be available in many professional disciplines and the closing session will feature a drawing for a free Quickie Wheelchair (you must be present to win). A limited number of scholarships and travel stipends are available to assist individuals with spinal cord disabilities in attending the conference.

The conference is sponsored by the Commission and the SCI Education and Training Foundation of the Paralyzed Veterans of America, in cooperation with our co-sponsors: HealthSouth Rehabilitation Hospitals of Arkansas, Snell Prosthetic and Orthotic Lab, Baptist Rehabilitation Institute, Hot Springs Rehabilitation Center, United Medical, Inc, Alliance/American Homepatient and Sunrise Medical.



Mark Wellman, opening keynote speaker at the 1998 conference, is pictured meeting the "Half Dome Challenge."

If you need more information, contact Dee Ledbetter at **1-800-459-1517** or **(501)-296-1784**. ♪

ASCC's New Website Online!

The Arkansas Spinal Cord Commission (ASCC) has launched its new website! Found at **www.state.ar.us/ascc**, the site includes information on our agency, services we provide, statistics on spinal cord disability in Arkansas and the United States, information concerning the Americans with Disabilities Act and contacts for other spinal cord disability resources. Our site even contains all 28 of ASCC's Fact Sheets!

So, next time you are on the internet, look us up. Remember, our address is **www.state.ar.us/ascc** — happy surfing! ♪

Dr. McCluer's Retirement Party



Past and present Commission members and staff, along with a few former colleagues and friends, celebrated Dr. Shirley McCluer's LAST retirement party on February 26, 1998. A part of the festivities included the dedication of the ASCC resource library as the *Shirley McCluer, M.D. Education and Resource Center on Spinal Cord Injury*. Commission Chair **Russell Patton III** (left) joins Dr. McCluer (right) in unveiling the Center plaque, while Case Manager **Dan Stell** (center) looks on.

SPINAL COURIER

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Cheryl L. Vines
Executive Director

Thomas L. Farley
Dee Ledbetter
Co-Editors

Commission Members:
Russell Patton, Chair
Sheila Galbraith Bronfman
Sandra Turner
Deanna Van Hook
James Miller

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BUCKLE UP!

With Thanks

ASCC accepts tax deductible donations. The generosity of the many individuals and families who over the years have made memorial donations is greatly appreciated. Contributions are used to assist our clients through purchases of equipment and educational resources.

If you would like to make a contribution, please contact the Commission at (501) 296-1788 / (800) 459-1517 / TDD (501) 296-1794 or send your donation to:

AR Spinal Cord Commission
1501 North University, Suite 470
Little Rock, AR 72207

Donations this quarter from:

Katherine Burnett
Debbie Dean
Claudia Gardner
Doris Manning
Mary Middlesworth
Wayne Rose

In honor of Dr. McCluer
Linda Shearer

In Memory of Murray Linam
Linda Shearer

SPINAL COURIER Letters

Questions • Suggestions • Directions • Answers

Female Sexuality Study

Dear Editor:

Attention female *Spinal Courier* readers! If your injury is T-6, complete, or below, you may be interested in participating in an Americal Paralysis Association Grant funded by **Beverly Whipple**, Ph.D. She and **Marca Sipski** are the foremost researchers in the world in SCI female sexuality. This would require traveling to Bowman Gray School of Medicine for a PET brain scan, but all expenses would be paid.

For details, please contact me in the UAB Urology Division by calling **1-800-333-6543**. If I am with a patient, please leave your name and number and I will return your call. You can also reach me by calling **(205) 934-9008**.

This is a great way to travel to North Carolina for free, as well as to help us learn more about female sexuality at the same time.

Jane F. Brown, MA
AASECT Certified Sex Therapist
UAB Urology Division
Birmingham, AL

From the Director

"Learn one new thing every day," my mother challenged me when I was about eight. That was quite an undertaking, probably more for figuring out what I had learned than actually learning it. Often we reported our newly learned word, fact or idea over dinner, sharing our insights. Though the fun of reporting it wore old after a while, I've never forgotten it.

Today, with technology, fifty TV channels and more "information" than any one person can comprehend, I feel challenged by a different game — figuring out what is worth learning and trying to keep in my over crowded memory! We "learn" so much every day! How do I decide what to believe? How do you? Just because I found it on the internet, should I believe that people with spinal cord injuries are being "cured" with shark cartilage injections at a clinic in Mexico? Who put that information there? Are those photo images to be believed or are they like the pictures on the tabloids at the grocery store — a mosaic of different pictures put together to attract attention?

Taking the information that we receive and figuring out how to use it is becoming a great challenge as we face the new century. It is up to each of us to be responsible consumers, whether it is about health information, financial resources or the latest gossip.

If it sounds too good to be true — it probably is! Check out information with people you know and trust before accepting it as fact. One good way to check out facts and information is at our *Living With Spinal Cord Disability: Strategies for a New Century* conference on May 1 & 2, 1998. We will have experts in many areas of spinal cord injury care, treatment and living with spinal cord disability available to present new information and back it up with facts! This is your opportunity to learn something new and get your questions answered! Don't miss it! I'll be there, trying to figure out how to fit some more new "stuff" into this poor old brain of mine!

Cheryl L. Vines

Tyler Garner Chosen to Represent Arkansas on IronKids Team

Tyler Garner, a sixth grade student at Lake Hamilton Middle School, was chosen from more than 4,000 kids nationwide to the 1997 All-American IronKids Bread Team. He was selected to this honor by winning an essay contest sponsored by IronKids Bread which asked kids ages 7 to 14 around the country to describe

what they do to be the best person possible in areas such as exercise/nutrition, schoolwork and other interests and activities. In addition to being chosen to represent Arkansas on the eight member IronKids Team, Tyler received a \$2,500 savings bond for college. Following is Tyler's winning essay.

What "You Can Do It" Means to Me

By Tyler Garner

All of my life I've seen people who don't try new things because they're embarrassed or afraid they'll fail. I think this is sad to me. They need to get the message that yes, "You Can Do It" from someone or something that is important in their life so that they will listen. "You Can Do It" is an important and powerful lesson if they will listen. I think "You Can Do It" is an inspiration for people just getting involved in sports and other hobbies.

I am very lucky because I have had a lot of opportunities in a variety of sports such as track and field, basketball, road racing, triathlons, cycling and swimming. I have had many people in my life who have told me that yes, I can do it. This is important. A lot of kids aren't as lucky as me because they haven't been encouraged to participate and push themselves.

I am eleven years old and was born with spina bifida and have been competing in a wheelchair for six years. I want to tell people that no matter what other people think, you have to believe in yourself and believe that "You Can Do It." If you will believe in yourself and try to be part of activities that are fun and are good for your health, other people will believe in you too! I hope that by participating in as many activities as I can I will lead a healthy life, and by doing this maybe I can send a message to other kids in wheelchairs that physical activities are not just for kids without disabilities. I want kids in wheelchairs to see and to know that "You Can Do It" too!!

Academic All American Team Announced

The inaugural National Wheelchair Basketball Association High School Academic All American team was announced at the National Wheelchair Basketball Tournament in Nashville, TN on March 19, 1998. From the 31 junior wheelchair basketball teams around the nation, ten academic All Americans were selected, based on their high

school grade point averages and activities.

Two of the ten were from the Arkansas Junior Rollin' Razorbacks team! The Arkansas Spinal Cord Commission members and staff join the Rollin' Razorbacks and Junior Rollin' Razorbacks in congratulating **Ashish Bkakta**, Hall High School, Little Rock and

New Face in Central Office



Cynthia L. (Cindy) Schoof joined the Commission staff as Administrative Assistant in the Central Office in December, 1997. Cindy is responsible for staff payroll, benefits and leave, as well as serving a secretary to the full Commission. In addition, Cindy has assumed the role of Spina Bifida Camp Coordinator for this summer's camp.

Cindy brings a wealth of knowledge and experience that will serve her well in this position. She holds a degree in Marketing from Louisiana State University at Shreveport and has extensive experience in payroll, personnel, program and policy development and computer skills. She comes to us from the Arkansas Heart Hospital where she was involved in the start up of the new hospital.

Cindy and her daughter live in Jacksonville. When she finds free time, she enjoys, hiking, camping and being outdoors. &

James Rucker, Mills University Studies High School, College Station, AR. Both Ashish and James are charter members of the Junior Rollin' Razorbacks and are high school seniors, graduating this spring. Great job, Ashish and James! &

Thanks Calvary Volunteers

One of the primary needs in returning home after a spinal cord injury is having a home that is accessible. For most people, this means a ramp must be built, just to allow them to get in and out of their home. A ramp is an expense that is not covered by insurance and can be quite costly. Case Managers at ASCC have been able to utilize

some volunteer services through the City of Little Rock, but there is a long waiting list. Being confined to home waiting for your name to come up on the waiting list is not only frustrating, but is unsafe.

For several years, the Commission has been able to call on a group of retired men from Calvary Baptist Church in Little Rock to help. The Handyman Ministry, led by Harold Pless, began building ramps for church members and then responded to a need to help in the community. These men are "retired" only in that they have left their primary careers — they hardly slowed down after hanging up their professional attire. They have been busy in endeavors that have



Handyman Ministry volunteers, (left to right) Ivan Gibbons, Harold Pless and Conway Sawyers.

brought a great deal of satisfaction to themselves and joy to others. With skills they often did not use on their jobs, the members of the Handyman Ministry found they had a lot to offer persons with special needs. They began doing odd jobs for elderly persons and widows at church. The rewards were the smiles of homeowners who could never have done the jobs or hired someone to do them. At this time the "Handymen" have completed five ramps for clients of the Commission. Their work has been excellent.

Thank you, **Harold Pless, Conway Sawyers, Charles Dixon and Ivan Gibbons.** You are greatly appreciated!!! &

AR Junior Rollin' Razorbacks — Outstanding Organization of the Year

The Arkansas Junior Rollin' Razorback Wheelchair sports program was selected as the "Outstanding Organization" at The Greater Hot Springs Chamber of Commerce's annual Gala Banquet Celebration. The banquet, with over 450 persons in attendance, was the setting for the announcement and recognition of Community Service Awards, as reported in Hot Springs' *Sentinel-Record* of February 16, 1998. Nominated from within the com-

munity, the awards acknowledge the outstanding contributions by individuals, organizations and businesses throughout the year.

The Sentinel-Record noted, "The program's goals are to introduce competitive and recreational sports to children in Arkansas with orthopedic disabilities and to introduce exercise and fitness in a fun, positive atmosphere to this population . . . The activities of the (Junior) Rollin' Razorbacks

Spina Bifida Camp 1998

Hi Ho, Hi Ho, it's off to camp we go! That's right . . . spring has come and that means it's time to get ready for our annual Spina Bifida Camp. Every year, in cooperation with MedCamps of Arkansas, Inc. and Camp Aldersgate, Inc., the Arkansas Spinal Cord Commission sponsors camping for children between the ages of six and sixteen at Camp Aldersgate in West Little Rock. This year we will be sponsoring only one week, from **June 21 through June 28**, but the number of sponsored campers will remain the same as last year at 55.

For those of you who are unfamiliar with Spina Bifida Camp, here's the scoop. The MedCamp program features the traditional camping activities such as nature hikes, out-of-doors cooking, swimming, fishing, drama, music and arts and crafts that have been adapted so that each camper can participate to his or her fullest ability. All the cabins, dining hall, health care center and activity buildings are air conditioned and fully accessible. In addition, from the time camp starts on Sunday afternoon until camp ends on Friday morning, the campers are under one-to-one supervision with trained counselors and volunteers.

This really is a time of growth and learning for all the campers while they spend a week full of fun-filled activities. Applications and brochures will be sent out in April and acceptance will be based on a first-come, first-serve basis, so be sure to send yours in as soon as possible! &

are important not only for developing physical health and independent living skills, but also for contributing to the social, psychological and emotional development of these children." &

Skin & Nail Changes

Written by Samuel L. Stover, M.D.

We are all concerned about our skin and preventing pressure ulcers. There are some other skin changes that I became interested in during my years of practice. I thought they may have some significance to pressure ulcers.

One of the noticeable skin changes I first saw was in a young man whose skin had become hard and did not pinch like it usually did. The skin was shiny and taut and appeared swollen. A skin biopsy showed collagen or a protein type material in the skin. Some other UAB researchers and I examined his skin and found that the normal type three collagen, which gives our skin elasticity, was being replaced with a more dense and firm type of collagen.

After looking through medical texts, the best description that I could find said that "denervation" (loss of nerve control) does not lead to any definite change. However, I was seeing quite a few people who did have some difference in the skin after injury so I continued to study these changes.

During the three years from 1988 to 1991 we examined the skin of 679 individuals with SCI at the time of their annual clinic visits. In addition to the clinical skin and nail evaluation, we looked at the individual's history for autonomic dysreflexia and level of injury. Nail changes were the most common change seen. There was enlargement and thickening of the toenails seen in approximately 12% of the individuals. Statistically, there was no difference based on the level of injury.

We did see a much higher incidence of skin thickening in persons with injuries to the neck or tetraplegia or upper thoracic injury. The change occurs during

the first several years after injury and then it doesn't change very much. Up to about 50% of individuals with higher levels of injury have some skin thickening. We also saw a relationship between the level of injury, autonomic dysreflexia and the amount of skin thickening that individuals have.

In addition to the extra collagen that is present there is some swelling from the fluid content of the skin. I think that it is interesting that this may be a way for the body to lay down some extra padding to prevent skin ulcers. This condition of the skin does not seem to get worse. It may be a nuisance, but it doesn't lead to any other organ problems.

Another skin change that individuals with SCI may have is a reddening of the skin on the hands or around the nails. This does not seem to cause any problem. It does show there is a change in the circulation in various areas of the body.

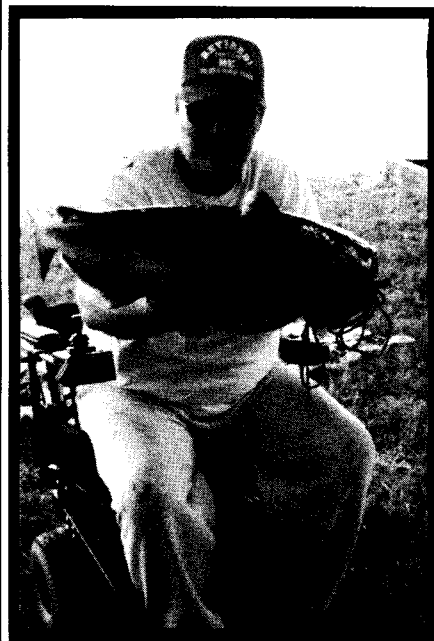
If you have areas of skin that just won't heal or look red and you don't think it is a pressure sore, have someone look at it. It is often a sign that there is an infection of the bone under that area. A bone infection can lead to an ulcer.

You can get infection of the skin from bacteria. A simple sore can become infected and become dangerous if it is not treated. There are certain types of soaps, such as Dial or Phisohex, that you can use daily for cleansing so you can prevent this type of infection. Rashes are often caused by a superficial fungus infection in the skin. These usually go away without treatment or there are treatments with skin ointments that can help.

The biggest problem is still pressure ulcers. The best thing to do is to prevent them from happening. If you have pressure ulcers, take care of them. Don't neglect the skin under any conditions. Caring for the skin can prevent many other problems. ♪

Taken from Pushin' On, Winter, 1996, at the University of Alabama at Birmingham, Spain Rehabilitation Center by the Medical RRTC in Secondary Conditions in Spinal Cord Injury, Birmingham, AL.

Danny Reels in the Big One!



Danny Longacre, pictured here, reeled in a 22-23 pound river catfish on October 2, 1997. While fishing with friends and family on the Arkansas River (using 25 lb. test line and chicken gizzards for bait), Danny felt this one grab his line. It took Danny 20 minutes to bring the fish into the boat.

SCI, Aging and Caregiving

By Richard Holiky, M.A.

Researchers continue to study the physical consequences of aging with spinal cord injury (SCI), but often ignore the other people in the SCI survivor's life. What happens to those around the survivor as they, too, age? An ongoing research project with long term survivors, sponsored in part by Craig Hospital, recently polled spouses of long-term survivors to learn more about what happens to caregivers and to their relationships over time. The findings reveal predictable areas of concern: emotional stress, role overload, more frequent health problems and changed family dynamics.

In the Craig study, 124 spouses of long-term spinal cord injured persons were surveyed. Ninety percent were women. Their average age was 52 and, on average, they had been married 29 years.

In general, the spouses reported being more depressed, having different priorities, and having their needs less well met than their SCI spouses or partners, according to several questionnaires which measured the depression, stress, needs and priorities each partner reported in his or her life.

In general, nondisabled spouses reported significantly more emotional symptoms of depression, like crying and feeling blue, than their SCI spouses. Nondisabled partners also showed more physical signs of depression as well, such as sleeplessness and loss of appetite.

Furthermore, nondisabled spouses had more stress, more nervousness and more feelings of being unable to cope than their disabled partners.

Finally, the SCI survivors and their spouses also had many differences in their priorities. Spouses

considered learning, creative expression, self-understanding, work and material comforts to be less important than their disabled partners. They rated having children as more important than their disabled partners. They said their needs for having a close relationship with their spouse were *less well* met than their SCI partners; and their needs to work or help others were lower.

But there's more: those wives and husbands — in this study, mostly wives — who had the dual role of spouse *and* personal care provider reported even more signs of depression — loss of appetite, sleeplessness, feeling sad, crying — than those not providing care. These caregiving spouses also reported more physical and emotional stress, anger, resentment, fatigue, as well as feeling happy less often than their non-caregiving counterparts.

*But, your needs are important as well. What's more, by not paying attention to those needs, you place **yourself** at risk of not being able to provide the level of care you **want** to provide, especially as you age.*

Results were analyzed in a variety of ways to identify the sources of stress, depression and negative emotions. Here's what we found:

- younger caregivers seemed to have more stress than older ones.
- younger caregivers and caregivers whose partners used condom catheters to manage their bladders had more depression.
- the act of caregiving itself

seemed to bring stress, nervousness and depression with it. In fact, it was the feelings of those who provided personal assistance that accounted for virtually all of the differences between spouses and their disabled partners.

In other words, nondisabled spouses or partners who provide care are at greater risk and more prone to depression, stress and nervousness than those partners and spouses who do not provide.

Studies of those who care for individuals with other disabilities have reported similar findings — unmet needs, differences in priorities, fatigue, anger, depression. In addition, they worry about the future — who will provide care when they become too old? Who will take care of them, if and when, they need help? Because of these similarities, there's reason to believe that what helps spouses of people with *other* disabilities will also help caregiving spouses of SCI survivors too. Some of the things that have been found to help are:

- maintaining equality within the relationship and finding ways for both partners to make significant and meaningful contributions — such as through working, parenting, various household chores or money management.
- maintaining family support and functioning especially during transition times such as moves, kids leaving home, starting or quitting work — by emphasizing the importance of each member to the family, keeping communications open through family meetings and staying in touch with extended family.
- getting help with those highly confining, restrictive and physically demanding tasks which place caregivers on someone else's

Continued on page 7 - see Caregiving

Are You a Family Caregiver ?

Caregivers are relatives, friends or neighbors who stand by their loved ones as they face chronic illness or disability. Caregivers are a diverse group of people of all ages and from all walks of life who share a common bond of helping others. Caregivers are special people who often receive little recognition and thanks for their efforts.

If you recognize yourself in this description, then the National Family Caregivers Association (NFCA) may be just what your looking for. The NFCA is a not-for-profit membership organization whose mission is to improve the overall quality of life of America's 25 million family caregivers. Membership is open to family caregivers, their friends and the professionals and institutions supporting them.

Through its services to members in the areas of education and information, support and validation, public awareness and advocacy, NFCA strives to minimize the disparity between a caregiver's quality of life and that of mainstream Americans.

Current services of NFCA include:

- a newsletter providing "can do" information, resources and questions and answers.
- a caregiver-to-caregiver support network to help caregivers find a friend in similar circumstances.
- cards for caregivers that provide a different upbeat message three times a year to remind caregivers they are not alone.
- *The Resourceful Caregiver*, NFCA's guide to helping caregivers take charge of their lives.

- the NFCA speaker's bureau whose members educate and inform professionals and caregivers from coast to coast.
- the NFCA Caregiver Member Survey Report that documents and validates the commonalities of the caregiver experience.
- National Family Caregivers Week Celebrations to raise public awareness and caregiver consciousness.

For more information or to receive a membership packet contact:

National Family Caregivers Assn.
9621 East Bexhill Drive
Kensington, MD 20895-3104
Phone: **301-942-6430**
1-800-896-3650
e-mail: **info@nfcacares.org**
FAX: **301-942-2302** &

Caregiving



Continued from page 6

schedule — doctor appointments, bathing, bowel programs, etc. — or getting help in times of greater need, such as when **you're** ill or need bed rest.

- having some backup help lined up available — relatives, friends, neighbors, Visiting Nurses Association, local volunteer organizations — **before** the need actually arises.

- keeping in touch with friends, having people over or visiting them, going out on your own occasionally — to help decrease isolation.

- joining or starting a caregiver support group — not to share war stories, but to share ideas, resources and coping skills.

- preserving your own help by exercising, eating well or managing stress, even if these activities cut into caregiving time.

- doing what it takes to feel in control — making and keeping

a schedule, making informed decisions.

- taking enough time for yourself to know when you need a vacation, a break, a night out or even time to be sick.

Caregiving spouses themselves talk about how important communication is between partners and within the family as a whole. They also talk about something called **respite care**. This allows caregivers to get away from relentless and potentially overwhelming responsibilities for a day or for several weeks by having skilled care personnel stay in the home, or by having their partner stay in a facility which provides as appropriate level of care. Check with home health agencies or Independent Living Centers for more information. As one longtime caregiver asks, "How many married couples spend 24 hours a day together — every day?" Your job as a caregiver may feel like it never ends. You may feel

as though your caregiving responsibilities are the most important ones you have. You may feel guilty if you occasionally take time to think about yourself. But, your needs are important as well. What's more, by not paying attention to those needs, you place **yourself** at risk of not being able to provide the level of care you **want** to provide, especially as **you** age. If caregiving is important to you, taking care of yourself and staying healthy emotionally, spiritually and physically will help insure that you will be much more able to give your spouse the help he or she needs. &

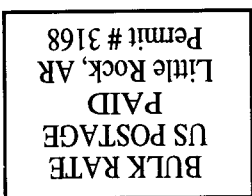
Reprinted from a fact sheet from Craig Hospital RRTC on Aging with Spinal Cord Injury. You may request a free copy of this and other informational sheets from Craig Hospital by contacting them via internet at: <http://www.craig.hospital.org/rehab> or by calling 1-800-5REHAB8 (573-4228).

New Items In the Shirley McCluer, M.D. Education and Resource Center

The Shirley McCluer, M.D. Resource Center on Spinal Cord Injury has obtained a number of great new resources during the last few months. Our new resources include the following books and videos:

- **"Camp Aldersgate Spina Bifida Camp"** (video) - a great way to see what camp is like!
- **"Pressure Ulcers: Causes and Prevention"** (video)
- **"Pressure Ulcer Management: Risk Factors and the Role of Nutrition"** (video)
- **"A Video Guide on Intermittent Self - Catheterization in Adults,"** available in Spanish and English
- **A Compendium of SCI Educational Resources,** a report developed under the sponsorship of the American Spinal Injury Association at TIRR (The Institute for Rehabilitation and Research), with the support from the Education and Training Foundation of Paralyzed Veterans of America
- **Interdependence: The Route to Community** by Al Conducci, a book concerned with reentry into the community of people with disabilities
- **Towards Intimacy: Family Planning and Sexuality Concerns of Physically Disabled Women** by the Task Force on Concerns of Physically Disabled Women
- **Towards Fitness: Guided Exercises to Those with Health Problems** by Robert C. Cantu, MD
- **Disabled Eve** by Brenda P. McCarthy, looks into assistive devices to aid disabled women during menstruation
- **Multiple Sclerosis: The Questions You Have and the Answers You Need** by Rosalind C. Kalb
- **Living with MS: A Guide for the Patient, Caregiver and Family** by David L. Carroll and Jon Dudley Dorman, MD
- **MS and the Family** by Rosalind C. Kalb and Labe C. Scheinberg

All of the above listed resources can be checked out of the Education and Resource Center for two weeks, free of charge. Please call Jenni at (501) 296-1792 or 1-800-459-1517. &



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Arkansas Spinal Cord Commission
1501 North University, Suite 470
Little Rock, AR 72207
Address Service Requested